



THE BEACON

Newsletter of the Wisconsin Deafblind Technical Assistance Project

Deaf-Blind to Deafblind: The Change

by Jodi Anderson, WDBTAP Family Specialist

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There is a change happening here at WDBTAP...we are losing a hyphen.

WDBTAP has made the decision to merge the two words Deaf-Blind into one word without a hyphen. This new word more accurately reflects the uniqueness of this disability.

Deafblindness isn't simply deafness plus blindness but the combination of the two creates something that is much bigger and more significant than the parts of the whole.

Deafblindness is a confusing and scary term. I know this is particularly true for families of children who have recently been diagnosed with vision and hearing issues. For this reason, I hear family members say that their children are not deafblind, but rather that their children have combined hearing and vision problems. Others ask why we use the term at all? I would give two main reasons for continuing its use. First, when a new child is entering a program, the term alerts teachers and administrators that there is visual and auditory information missing, decreased and/or distorted for the child which

can have a profound impact on how that child learns, communicates and interacts with the environment. Secondly, the term "deafblind" represents a community of children, youth and adults throughout the world with a rich and proud history of success, innovation, courage and undaunted spirit.

FOR FAMILIES OF CHILDREN WITH CHARGE SYNDROME: THE ETHAN WOLFE RECREATIONAL ASSISTANCE PROGRAM

The Ethan Wolfe Recreational Assistance Program provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. This program

is need-based and funded through a generous gift from The Wolfe family and friends. During Ethan Wolfe's 12 years of life, he rode an adaptive bike, attended special recreational camps, participated in swimming lessons and music class and so much more.

David & Jody Wolfe, together with the CHARGE Syndrome Foundation, wish to honor Ethan's memory by providing other individuals with CHARGE syndrome similar, fun activities and equipment that enriched his life.

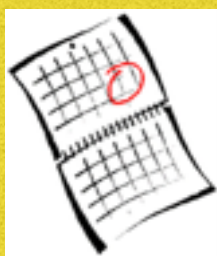
Examples of recreational items which would qualify (will be open to other suggestions):

- Adaptive recreational equipment not covered by insurance (examples: bike, swing)
- Adaptive sporting activities/teams (examples: baseball, soccer, gymnastics, swimming)
- Specialized camp (examples: summer camp for blind, deaf, special recreation)
- Special recreation programs (examples: community outings, science class, music class)



PLEASE GO TO THIS LINK TO REVIEW THIS EXCITING OPPORTUNITY:

[www.chargesyndrome.org/documents/
EthanWolfeRecreationalAssistanceProgram.pdf](http://www.chargesyndrome.org/documents/EthanWolfeRecreationalAssistanceProgram.pdf)



SAVE THE DATE:
**WESP-DHH Outreach Statewide Family and
Professional Conference**
October 22-25, 2015
Oconomowoc, WI

Look for more information coming soon!!

PERIODS OF TRANSITION

BY LYNN BREKKE

Last fall our advisory board met to discuss and set goals for our next 5-year grant cycle. One area that the board felt we needed to concentrate on is helping our families through the various transition periods their children face. We will focus on 3 areas of transition including:

- transition of children from Birth to 3 programming to elementary school
- transition from elementary school to secondary (middle and high) school
- transition to adulthood.

All of these transition periods can be scary and trying for families of children with special needs, and our goal at WDBTAP will be to provide our families with as much support

and information through these stages as we can.

From our recently completed 2014 census, we are gathering the data to identify which of our children are at or near a transition milestone, and those families will be receiving transition information from us.

We will also be highlighting transition information in our newsletter and including helpful links on our webpage.

Finally, we would really like to highlight some transition stories from our families, good or bad, *so if you have stories you would like to share, please email Lynn at Lynn.Brekke@wesp-dhh.wi.gov.*

Transition to Adulthood

For our students transitioning from high school to adulthood there are 3 key areas that need to be prepared for:

- healthcare
- school to work and
- community living

The purpose of the **health care team** is to plan and support transition from pediatric to adult health care. You can work with your child's health care team and school team to make sure health and medical goals are reflected in your child's **IEP**. The **health care team** includes you and your child, primary care provider, specialty care, medical care staff, and other health care providers.

The purpose of the **school team** is to develop and implement an **IEP**. The **school team** will work on the transition plan to be included in your child's **IEP**. The **school team** includes you and your child and everyone who is formally involved in developing your **IEP**. At a minimum, it must include: the student, one parent or your primary caregiver, a regular education teacher, a special education teacher, and a **Local Education Agent (LEA)** (a school district representative).



Periods of Transitions continued

The purpose of the **community living team** is to help you plan and support your transition to adult living, including your job and the informal supports and community-based services. The **community living team** includes everyone involved in helping you plan and live within your community, including county-based program staff.



Wisconsin Community of Practice on Transition; Practice Group on Health



What is ADRC?

For those transitioning to Adulthood ADRC is the place for information and assistance!

Aging and Disability Resource Centers (ADRCs) are the first place to go to get accurate, unbiased information on all aspects of life related to aging or living with a disability. ADRCs are friendly, welcoming places where anyone - individuals, concerned families or friends, or professionals working with issues related to aging or disabilities - can go for information tailored to their situation. The ADRC provides information on broad range of programs and services, helps people understand the various long term care options available to them, helps people apply for programs and benefits, and serves as the access point for publicly-funded long term care. These services can be provided at the ADRC, via telephone, or through a home visit, whichever is more convenient to the individual seeking help.

ADRC has a benefits specialist specifically for the deaf, hard of hearing and deafblind. You may choose to contact the Deaf Disability Benefit Specialist at the Office for the Deaf and Hard of Hearing, Jennifer Koehn at 262-347-3045.

WDBTAP STAFF

Marcy Dicker, Project Director
Jolene Gruber, Grant Coordinator
Heidi Hollenberger, Deafblind Consultant
Jodi Anderson, Family Specialist
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Students with Disabilities Can Now Access On-Demand Children's TV Programming

Thousands of students with visual or hearing disabilities can now access free, video-on-demand children's television programming.

Dozens of children's and family TV episodes may now be viewed online featuring closed captioning and descriptions through our Accessible Television Portal project. Among the shows: "Ocean Mysteries," "Magic School Bus," "Bill Nye the Science Guy," "Daniel Tiger's Neighborhood," "Expedition Wild" and "Peg + Cat."

The portal is part of the Department-funded Described and Captioned Media Program (DCMP). It includes video-on-demand content provided at no cost by the major television networks, as well as producers and distributors like PBS Kids, Sesame Workshop, Cartoon Network, Sprout (NBC), the Fred Rogers Company, Scholastic Media, Litton Entertainment, Out of the

Blue and Fremantle Television.

"In the digital age, the capability exists to deliver a higher level of personalized programming for students who were underserved in the past," said Secretary Arne Duncan. "This type of large-scale collaboration



between the Education Department and so many major television networks, producers and program distributors will allow greater access to television programming for all students."

To view the content, teachers and school personnel, parents, and other professionals working with qualified students can visit www.dcmp.org and apply for access to the portal.

Once approved, accessible content can be used with, and by, students in the classroom and at home via the Web, mobile phones and tablets, mobile apps, and set-top boxes. The portal itself is fully accessible to those with sensory impairments. Children with disabilities can locate any featured program without difficulty.

Initially, the site will include 73 episodes of 19 different children's television programs. Additional content from other producers will be added over the next two years.

~~from HOMEROOM; the Official Blog of the US Department of Education

Upcoming Events for our Families



2015 WCBVI Conference for Families of Children with Blindness or Visual Impairments Birth to 21

Heidi Hollenberger and Jodi Anderson from WDBTAP will be on-hand to help support our families of children with combined vision and hearing loss. WDBTAP will be able to assist with some scholarships. Look for more information in emails and on the website as the date approaches.

When: June 19-21, 2015

Where: Wisconsin School
for the Blind and
Visually Impaired
(1700 West State
Street, Janesville)

Cost: \$50

*families will be staying in the dorms



Teen Getaway Weekend Sr Friday, May 8 to Sunday, May 10, 2015

Getaway Weekend is a program offered to students in the state who are deaf, hard of hearing and deaf-blind, for a minimal registration fee of \$50. Transportation to and from the camp is provided. The goal of the weekend is to provide an opportunity for students to meet other students and gain exposure to the variety of students and adults who are deaf, hard of hearing, and deaf-blind and to increase interpersonal communication skills through interactions with others in a supportive and accessible environment.

OLYMPIC DAY!!!!

CESA 4 and WESP-DHH Outreach are partnering to bring deaf, hard of hearing and deafblind students from Wisconsin, Minnesota and Iowa a day full of fun and socializing!

Deaf professional UFC wrestler, **Matt Hamill** and Deaf magician, **Magic Morgan** will give presentations that will **Wow** the audience.



You don't want to miss them!

Bring gym shoes, a swim suit, towel and lunch. This event is free to all D/HH/DB children, their families and professionals who work with them. **Interpreters will be provided.**

Please pre-register at: <http://goo.gl/qixL3Z>

WHERE: YMCA-North 400 Mason Street Onalaska WI 54650

WHEN: MAY 7, 2015; 10:40 AM to 2:00 PM (Check-in begins at 10:30 AM)



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Project Officer, Louise Tripoli-Louise.Tripoli@ed.gov

What Types of Technical Assistance does WDBTAP provide?

- Parent/Family trainings and assistance in connecting families with one another
- Statewide and regional workshops for service providers and families
- Observation, support and coaching in programming for children
- Intensive deafblind training series for paraprofessionals who work one on one with children and youth who are deafblind
- Assistance in identifying children and youth who are deafblind
- Referral to relevant local, regional, and national agencies
- Lending library with materials, equipment, and toys to benefit deafblind children/youth on the Registry

Wisconsin Deafblind Technical Assistance Project

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